



Patient-Centered Care: What Consumers and Families Want

A DISCUSSION FEATURING:

Beverley H. Johnson

President and Chief Executive Officer

Institute for Patient- and Family-Centered Care

Dorothy Jeffress

Executive Director

Center for Advancing Health

Christine Bechtel

Vice President

National Partnership for Women & Families

FORUM SESSION ANNOUNCEMENT

FRIDAY, OCTOBER 1, 2010

11:45AM–12:15PM—Lunch

12:15PM–2:00PM—Discussion

LOCATION

Reserve Officers Association
One Constitution Avenue, NE
Congressional Hall of Honor
Fifth Floor

*(Across from the Dirksen
Senate Office Building)*

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“Patient-centeredness” was one of six aims for delivery system improvement set forth by the Institute of Medicine (IOM) in its landmark 2001 report, *Crossing the Quality Chasm*; the hope was that achieving all six would also mean achieving a high-quality health system for the 21st century. The IOM defined patient-centeredness as “providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions.”¹

The Patient Protection and Affordable Care Act (PPACA) contains a number of provisions that endorse the concept of patient-centeredness, particularly with respect to coordination of care. Among these are pilot programs for integrated care of hospitalized Medicare beneficiaries, grants for community-based health teams to support primary care practices, authorization of state plan amendments to support medical homes for Medicaid beneficiaries, and access to health risk assessment and medication management processes under Medicare. Many of the specifics remain to be defined by the Secretary of Health and Human Services.

Over the last decade, others besides the IOM have offered definitions of patient-centeredness. For example, the Institute for Patient- and Family-Centered Care (IPFCC) would like to see “an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families.”² Indeed, some suggest that careful definitions of “patient” and “family” should be the beginning of the process. In a commentary in the *Journal of the American Medical Association*, California physician Alexander Kon cautions that “patient” must incorporate the patient’s agent or surrogate decision maker when a patient is incompetent.³ IPFCC speaks of a patient’s “care partner(s)” as a person or persons designated by the patient as such, not necessarily his next of kin.

Donald Berwick, now the administrator of the Centers for Medicare & Medicaid Services, earlier proposed defining patient-centered care quite broadly: “the experience (to the extent the informed, individual patient desires it) of transparency, individualism, recognition, respect, dignity, and choice in all matters, without exception, related to one’s person, circumstances, and relationships in health care.”⁴

All of this sounds good. Like safe care or timely care, who could argue with patient-centered care? But it also sounds a bit fuzzy. Have we made progress toward patient-centered care? And how would we know?

Signs of progress can be pointed to. Consumer groups have become quite active in the policy arena, participating in deliberations, both public and private, such as those being held by the Agency for Healthcare Research and Quality, the National Quality Forum, the National Committee for Quality Assurance (NCQA), the Joint Commission, and even the Office of the National Coordinator for Health Information Technology (ONC). For example, the National Partnership for Women & Families spearheaded a coalition of consumer and employer groups that urged the ONC to maintain a robust definition of “meaningful use” that included requirements for patient access to information and patient and family engagement.

What consumer groups seek is more tangible than clinicians’ being more considerate. They want patients and families to share power with clinicians in developing care plans, understanding the potential benefits and risks of treatment alternatives, and making decisions. To be capable of this collaboration, proponents emphasize, individuals must have access to full and reliable information, support for self-management, and the trust and respect of their doctor and/or clinical team.

The attributes that consumers want patient-centered care to comprise, as laid out by the National Partnership, include the following:

Whole-person care—A patient with multiple diagnoses may see multiple specialists, without any one clinician’s taking responsibility for the patient’s overall well-being. On the clinician’s part, this would require taking the time to recognize all the factors that may affect a patient’s ability to get well, a range that could incorporate everything from child care concerns to religious belief to difficulty coping with medication packaging.

Communication and coordination—Patients value the idea that their doctors will talk to one another and that someone will watch over their care across providers and settings. Some multispecialty group practices and integrated delivery systems are able to offer “seamless” care, generally with the help of an electronic health record. Many doctors in solo or small practices report that they have little leverage with specialists and are not reimbursed for time spent on care coordination.

Patient empowerment—Patients want good information, speedy access to care, tools to help them better manage their conditions, connection to nonclinical support services as needed, and a recognized role for their trusted family member or friend.⁵

The topic of patient empowerment and shared decision making often raises the question, but what if a patient doesn't *want* the responsibility? In Berwick's vision, the patient would be free to adopt a "whatever you say, doc" approach. But a culture shift is in the works, at least among educated consumers who are used to making their own travel arrangements, managing their finances on line, and employing Google as their research strategy. Some members of this group feel strongly that they alone are ultimately responsible for their own care. What they want from physicians and other caregivers are the tools they need to manage their health. They push for "participatory medicine" with greater "patient engagement" in the health care system, as distinct from patient-centeredness, which may carry the implication that the patient's central role is still a passive one. Most people likely favor responsibility shared between patients and clinicians.

The movement to patient-centeredness or patient engagement is still gathering momentum, and the role for policymakers is not yet well defined. However, as pilot programs are being designed and regulations written to implement the PPACA, it probably behooves their architects to nourish a patient-centered consciousness of their own.

SESSION

This Forum session will explore the concept of patient-centered care and assess progress made toward achieving it in the years since the *Quality Chasm* report. It will consider a range of views on the part of patients and families and what consumer groups want to see change in medical practice after health reform. This is the first of a two-part look at patient-centered care. Part 2, scheduled for October 22, will consider providers' responses. (A separate meeting announcement will be e-mailed.)

SPEAKERS

Beverley Johnson, president and chief executive officer of the Institute for Patient- and Family-Centered Care, will provide an overview and some case examples of consumer goals in improving patient-centeredness and processes that are available to help clinicians move in that direction. **Dorothy Jeffress**, executive director of the Center for Advancing Health, will talk about the resources available to patients as well as the barriers to patients' becoming well-informed about and integrally involved in their care. **Christine Bechtel**, vice president of the National Partnership for Women & Families, will

conclude with a consideration of the issues that policymakers should be thinking about.

KEY QUESTIONS

- How can patients be prepared with the knowledge and confidence to make informed choices consistent with their preferences?
- How can sufficient patient-specific educational materials be developed and effectively disseminated?
- What are the implications of greater transparency of clinical information to the patient?
- Will physicians allow patients to be true partners in their care? How will physicians respond to patients whose decisions contradict their clinical judgment?
- How will the question of patient lifestyle choices play out in a patient-centered practice?
- What incentives might be put in place to encourage care coordination and communication among clinicians?
- How can quality measurement better reflect the patient experience of care?

ENDNOTES

1. Institute of Medicine, *Crossing the Quality Chasm* (Washington, DC: National Academy Press, 2001), p. 6; available at www.nap.edu/books/0309072808/html/.
2. Bev Johnson *et al.*, *Partnering with Patients and Family to Design a Patient- and Family-Centered Health Care System* (Bethesda, MD: Institute for Family-Centered Care, April 2008), p. vi; available at www.ipfcc.org/pdf/PartneringwithPatientsandFamilies.pdf.
3. Alexander A. Kon, "The Shared Decision-Making Continuum," *Journal of the American Medical Association*, 304, no. 8 (August 25, 2010): p. 903; available with subscription at <http://jama.ama-assn.org/cgi/reprint/304/8/903>.
4. Donald M. Berwick, "What 'Patient-Centered' Care Ought to Look Like: Confessions of an Extremist," *Health Affairs*, Web Exclusive (May 19, 2009) pp. w555–564; available at <http://content.healthaffairs.org/cgi/content/abstract/28/4/w555>.
5. Christine Bechtel and Debra L. Ness, "If You Build It, Will They Come? Designing Truly Patient-Centered Care," *Health Affairs*, 29, no. 5 (May 2010): p. 914; available with subscription at <http://content.healthaffairs.org/cgi/content/full/29/5/914?maxtoshow=&hits=10&RESULTFORMAT=&fulltext=ness&searchid=1&FIRSTINDEX=0&resourcetype=HWCIT>.